DOCUMENT RESUME

ED 258 581 EC 172 750

AUTHOR Cortez, Patricia
TITLE Deinstitutionalization of the Mentally Retarded.
PUB DATE [83]
NOTE 19p.
PUB TYPE Information Analyses (070)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Behavior Change; Community Programs; *Deinstitutionalization (of Disabled); *Mental Retardation; *Placement; *Trend Analysis

ABSTRACT

Literature on deinstitutionalization of mentally retarded persons is reviewed. Cited are studies showing positive aspects, including improved communication abilities, increased adaptive behavior and personal satisfaction. Community adjustment findings focus on effects of involuntary relocation to another facility, age differences, and reinstitutionalization. Studies of variables related to community placement failure are noted; these include caretaker experience and resident age, I.Q., and level of adaptive behavior. A review of national trends in deinstitutionalization shows substantial increases in releases from large institutions along with even more rapid increases in readmissions. Also noted is the emergence of a countertrend toward institutionalization, and the suggestion that there may be no significant difference between institution size per se and quality of care. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED258381

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)
✓ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

DEINSTITUTIONALIZATION
of the
MENTALLY RETARDED

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Patricia Cortez
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Patricia Cortez
927 Church Lane
Yeadon, Pa. 19050

EC 172750

Since the early 1970's the trend towards deinstitutionalization has affected many mentally retarded people. Institutionalized retarded people have been moved from state institutions to different communal alternatives such as: foster homes, group homes, and their natural families.

Deinstitutionalization is based upon the assumption that the quality of life, personal care, adaptive behavior, social skills, and independent functioning for retarded people will be significantly improved by placement in the community. Professional literature is replete with studies that illustrate the benefits as well as some of the negative effects of deinstitutionalization. Comparative studies of alternative living arrangements have also been examined.

In this paper an overview of the salient aspects related to the topic of deinstitutionalization will be presented. The articles chosen for inclusion in this paper exemplify much of the current thinking, directions, and research-related considerations for an objective appraisal of the topic of deinstitutionalization.

The positive aspects of deinstitutionalization are depicted in an article by Gilbert and Hemming (1979). Gilbert and Hemming hypothesized that retarded adults who transferred to small family units do not improve in their linguistic abilities moreso than retarded adults who remain in institutions. The sample in the study consisted of 29 mentally retarded adults (with a median I.Q. of 50)--these 29 mentally retarded adults were transferred from large institutions to 8-bed bungalows. Linguistic abilities of the transfer and control groups were assessed prior to, and nine months after transfer using the I.T.P.A. in conjunction with 5-minute

interviews. No significant results were found between the control and the transfer groups prior to the transfer. The second assessment (nine months after transfer) showed that psycholinguistic ability improved significantly for the transferred residents. The transferred residents increased the number of words used in response to simple questions. The results also indicated that the staff at the bungalows had incorporated more resident-oriented management practices (as opposed to institution-oriented practices) and more staff-resident interaction than the large institutions.

Much of deinstitutionalization has to do with normalizing the environment. It is believed that by exposing the mentally retarded to as normal an environment as possible that normative behaviors will transpire. In her study, MacEachron (1983) tested the hypothesis that normalized environments lead to more normalized behavior. More specifically, the study measured the effects of normalized cottages on the adaptive behavior scores of mentally retarded residents.

Institutionalized residents were randomly assigned to live in fifteen new residences (that were designed to be more normalizing in terms of physical and social features) or in fourteen older institutional buildings designed for custodial care. There were 160 residents in the experimental group and 129 residents in the control group. (For both groups the average I.Q. and the average age was 23 and 32 respectively.) Treatment consisted of either living in a new cottage for one year or living in an older institution. The physical environment was assessed in terms of the number of clients, home-like features, and the extent to which

residents were allowed to use the physical environment at their discretion. The social normalization of the residents' environments were also assessed. The items measured were the extent of resident-oriented interaction, the extent of resident programming, and staff/client ratios. Adaptive behavior of the residents was assessed after one year using the ABS (Adaptive Behavior Scale). As predicted, MacEachron's (1983) results have indicated that the experimental group (in the cottages) had a higher total adaptive behavior mean than the control group (in the institutions). Seven of the fifteen experimental groups had significantly higher means than the control groups. Overall, all fifteen experimental groups had higher means in their favor. A two-year follow-up indicated that the transferred residents improved in independent functioning, physical development, language development, number ability, domestic activity, self-direction, and responsibility at various times. The strongest predictor of adaptive behavior was higher I.Q. However, the treatment effect remained significant even after I.Q. had been controlled. Other strong predictors of adaptive behavior were participation in programs, extent of resident-oriented management practices, and the extent of residents' accessibility to the physical environment.

The positive effects of deinstitutionalization were also underscored in a study by Kleinberg and Galligan (1983). In this study, twenty mentally retarded people (with a mean I.Q. of 23.8 and a mean age of 46.3) were transferred from a large developmental center to small community residences. Two instruments were used for measuring behavior: the ABS and the Minnesota Developmental

Programming System. Adaptive behavior was assessed prior to 4, 8, and 12 months after placement. The results indicated that there was a net increase in several areas of adaptive behavior over the time spanned. Language development, domestic activity, responsibility, and social interaction increased but most of the increases occurred immediately after community placement. The results stabilized with few variations. The results of other studies were cited in the article--the results were similar. There was rapid improvement in the areas of language development, domestic activity, and socialization. In light of the results of other studies, it was hypothesized (Kleinberg and Galligan, 1983) that the rapid initial improvement in adaptive behavior scores in the community setting reflected increased opportunities to engage in domestic and social activities. The new environment was more conducive to manifesting these skills than the institutional environment. Another item worthy of mention is the fact that lower functioning residents (with I.Q.s below 20) showed increases in antisocial behavior. It was suggested that the lower functioning residents would be more receptive to behavior shaping programs during the increased activity period.

In another study by Schroeder and Henes (1978), it was shown that nineteen mentally retarded residents (mean chronological and mean mental ages were 29.3 and 5.2 respectively) made more gains in skills after placements in group homes than their matched control group in the institution. Specifically, the group home residents showed significant gains in the communication domain, as assessed by the Progress Assessment Chart. It was mentioned that this particular group home environment may have encouraged more use of

these skills.

The behavioral, social, and attitudinal effects of living in an urban community residence for two years was studied by Birenbaum and Re (1979). Interviews were conducted with a cohort of sixty-three mentally retarded adults at four different points in time. The purpose of the study was to assess the changes in behavior and attitudes towards community living, given the natural changes in the micro- and macro-environments. Overall, the attitudes of the residents towards community living and the staff remained favorable. In comparison to former state schools, residents stated that they liked the increased freedom that came with decision-making. Most residents maintained some personal relations with peers and were active in sheltered workshops. Between 1975-1977 staff-led activities were reduced by approximately 75% which ultimately decreased the amount of time residents were able to participate in the wider community during their leisure time. Self-initiated activities in the wider community were discouraged but not forbidden; noticeable was the general lack of skills in travelling to distant places. Trends towards increased responsibility, increased self-reliance, and personal regulation of daily activities were noted by the fourth interview. A significant number of residents complained about their lack of independence and more than half of the group (57%) expressed desires to live elsewhere (such as in an apartment, or with their families).

Even though the residents specified their dissatisfactions with certain aspects of community living, most favored living there than in state schools. It has been speculated that

decreased self-reliance may be indicative of changes in residential management techniques or of residents' incompetence in engaging in community activities.

Scheerenberger and Felsenthal (1977) conducted interviews with seventy-five former residents of a public residential facility in order to discern the attitudes and impressions of living in the community. The sample consisted of twenty-five foster home residents, twenty-five group home residents, and twenty-five adult home residents. (Their median I.Q.s were 58, 50, and 48 respectively--their median chronological ages were 12.8, 27.0, and 44.7 respectively.) Each resident responded orally to a questionnaire about the community setting. The results of the questionnaire indicated that generally, most of the residents who preferred living in the community, had a variety of leisure time activities, had a job which they enjoyed, had personal relationships within and without the home, were accompanied to places outside the community, and had money to spend in any way they desired. In addition to the positive aspects that were noted, there were negative aspects noted about the settings as reflected in the residents' responses. Few residents had any part in selecting their jobs; some had no personal allowances. Furthermore, most residents were accompanied on trips and many had to adhere to a strict bedtime schedule. Overall, many of the residents were making successful adjustments to community living and only a few expressed any desire to return to an institutional setting.

Involuntary relocation to another facility can be a positive or a negative experience depending on the coping skills of the individuals involved. The impact of interinstitutional relocation

was investigated by Cohen, Conroy, Frazer, Snelbecker, and Spreat (1977). The subjects in the study consisted of a skilled nursing group (with a mean I.Q. of less than 20) and an intermediate care group (with a mean I.Q. of 35) who transferred from a large institution to a smaller facility. The Adaptive Behavior Scale was administered to assess the effects of relocation one week before, one week after, and six to eight weeks after relocation. The intermediate care group showed a significant deterioration over time in independent functioning, economic activity, and language development. Significant improvement was noted in the reduction of antisocial behavior; conversely, withdrawal behavior increased for this group.

The skilled nursing group showed significant improvement over time in domestic activity, self-direction, and responsibility. In addition, rebellious behavior, antisocial behavior, and stereotyped behavior increased. Generally, the skilled nursing group exhibited higher adaptive and maladaptive behaviors while the intermediate care group exhibited lower adaptive and maladaptive behaviors. The evidence indicated that short-term changes in adaptive behavior accompanied the interinstitutional relocation of these mentally retarded people. It was suggested that clients with increased activity levels may be more receptive to behavioral interventions. Worth mentioning is the fact that the potential benefits should outweigh the potential risks when considering the transfer of residents from one place to another (Cohen et al., 1977).

Seltzer, Seltzer, and Sherwood (1982) studied the age variable and its relationship to community adjustment. The sample studied

consisted of 153 deinstitutionalized mentally retarded adults. Residents from 18-54 years of age were compared with those who were 55 and over. The two groups did not differ with respect to I.Q., level of retardation, recidivism, and the number of medical problems. The results showed that the older group functioned at a consistently lower level than the younger group in community living skills; the older group also lived in more restrictive, less autonomous environments. The possible explanations for the older group's lower level of functioning were fewer support services, less favorable environmental influences, and more severe medical problems.

Community placement stability and its relationship to community placement types were studied by Reagan, Murphy, Hill, and Thomas (1980). Data was collected on 186 behavior problem EMR adolescents who were transferred from a learning center to either natural, foster, or group homes. The average age and average I.Q. was 15 and 70 respectively. Follow-up data were collected at 6, 12, and 18 months after discharge from the learning center. Results showed that the greatest placement stability occurred for students who were initially placed in their natural homes. The data for foster and group home placement generally indicated decreasing placement stability, but this was largely a result of movement to less restrictive settings. Successful community placements can be further maximized by more research that will identify the variables to consider when matching the behavioral characteristics of residents and the social/physical characteristics of the community settings (Reagan et al., 1980).

Willer and Intagliata (1982) comparatively studied the

behavioral impacts of foster family and group homes on 338 deinstitutionalized mentally retarded adults. (The mean age of the adults was 45.) There were more SPI adults who lived in the foster family home than in the group home (40.1% vs. 29.5%); behaviorally there were no significant differences between the two groups at the onset of the study. The results of the Retrospective Problem Scale and The Devereux Behavior Rating Scale indicated that group home residents had more overt behavior problems (i.e., poor emotional control, need for approval, and inability to delay gratification) than foster family home residents. Conversely, group home residents made more significant gains in community living skills. There were no significant differences between group home residents and foster home residents with regard to self-help skills, interpersonal relations with friends/family, and ability to utilize community resources. A differential use of family-care and group homes was suggested.

In another study, Intagliata and Willer (1982) compared the characteristics of residents who were living successfully in the community but who were previously reinstitutionalized with those residents who had remained continuously in the community since their initial placement from an institution. The sample included 301 people from family care and group homes (n=201 and 100 respectively); 62.2% of the residents were mildly/moderately retarded and 37.8% of the residents were severely/profoundly retarded; the average age for both the return group and the non-return group was 45.1 years. There were no significant differences between the groups with regard to age, sex, and level of retardation. Adaptive behavior skills were assessed prior to, and

two years after community placement using the Devereux Scale. Results indicated that the return group could be discriminated from the non-return group primarily by their higher levels of maladaptive behavior. The return group showed greater frequency of problem behavior in all of the areas rated. The Devereux subscales significantly discriminated between returnees and non-returnees, especially among group home residents. Returnees were also more likely to travel in the community independently than non-returnees. The author of this article suggested that the behavioral problems could have been caused by deficiencies in the community settings or by the lack of tolerance for misbehavior on the caretakers' part.

Training programs for managing residents' behavior and steps for rectifying deficiencies in placement settings were proposed.

Much research has been directed toward discerning the variables that are related to community placement failure. Many studies have shown a relationship between certain client characteristics and community placement failure. In one study, a relationship was shown between caretaker characteristics, proximity of caretakers' families living in the community, and placement failure (Sutter, 1980).

The sample in the study consisted of 77 caretakers who owned and operated small family residences. Demographic variables such as age, sex, education, type of training, years of experience, and family organization were assessed by an 18-item survey. Clients were assessed in terms of age, sex, level of retardation, and adaptive behavioral level.

On the basis of records of client returns to the state

institution, data were categorized into two groups: a return group and a non-return group. Client characteristics for the two groups were similar except for age which was not considered to be a confounding variable in the study. Overall, the study indicated that there was a significant relationship between the amount of experience a caretaker had in working with the mentally retarded and client placement failure. Caretakers who had five or more years of experience in working with the mentally retarded had significantly fewer clients who had to be reinstitutionalized. Another finding was the relationship between the proximity of the caretakers' families and placement failure. Homes in which additional family members lived had significantly higher failure rates. Family members who lived near the homes had lower failure rates. The author of the study suggested that the caretakers with five or more years of experience may have developed management techniques that less experienced caretakers had not yet acquired; the homes that had relatives living nearby (vs. relatives living in the family residences) provided additional help and support only on an as-needed basis.

Many investigators have studied the I.Q. variable as a factor in community adjustment. Only about half of the studies found any relationship between I.Q. and community adjustment. Bell (1976) investigated the relationship between I.Q. and community life style.

Questionnaires were sent to 503 individuals who were discharged from 10 state schools. Residents with I.Q. scores above 55 and residents with I.Q. scores below 55 were studied. Bell found that a greater percentage of the higher ability group lived independently, were

employed, and were married or dating. With regard to law-abiding behavior, a greater percentage of the higher ability group were arrested. The trends for participating in community activities and frequency of social contacts were generally greater for the higher ability group. An interesting point is the fact that a higher percentage of this group also received assistance from agencies and organizations while in the community. A higher percentage of the high ability group received pre-vocational and independent living training while in the institution. The article suggests that steps need to be taken to avert the inequities of service delivery for the mentally retarded. I.Q.-related lifestyle differences may be a factor in community placement, but according to this study, I.Q. should be considered only after all ability groups have received equal support services and training.

In a study by Nihira and Nihira (1975), the adaptive behaviors of 424 community placed retarded persons were ascertained through interviews with 109 caretakers. From the 1,252 incidents of problem behavior cited, 203 of the incidents were judged to contain real or potential jeopardy to health/safety (77%), to general welfare (4%), or legal jeopardy (18%). The number of moderately, severely, or profoundly retarded clients who experienced incidents of jeopardy to health/safety and welfare exceeded the number of borderline/mildly retarded clients who experienced jeopardy in these areas. Incidents involving legal jeopardy were primarily concentrated among the borderline or mildly retarded clients. The author discussed the need for more effective care and the need for improved safeguards for all clients being placed in the community.

In another study, an examination of one institution was under-

taken to determine what criteria were used in the decision process when making placement recommendations for retarded persons. In their study, Vitello, Atthowe, and Cadwell (1983) found that more intelligent residents who had better adaptive skills were placed in less restrictive settings. In general, the highest functioning persons were recommended for group home placements whereas the lowest functioning persons remained in the institution. The residents who were recommended for skill development homes, for the most part, did not master the prerequisite skills that are required for self-sufficiency in the community. About one-third of the 28 discharged residents were placed in settings for which they were not recommended. The authors of this study suggested that other factors, such as placement availability and parents' reactions, may have determined final placement decisions. The article emphasized the importance of an optimal person-environment fit when arranging community placements for mentally retarded persons.

Ellis, Bostick, Moore, and Taylor (1981) conducted a follow-up study on 131 SPI children (with a mean I.Q. of 17.6) who received intensive training in self-help skills in a short-term institution. The study consisted of an evaluation of institutional records and an assessment of functioning on the ABS. The results indicated that the intensive training experience lead some parents to keep their child at home and others to place their child in an institution on a long-term basis. Various reasons were given for the parents' decisions. After the intensive training in self-help skills, many parents decided to keep their children at home because they became less of a burden. Other parents decided to reinstitutionalize their children because of the positive results

of the training--the institution was seen as a permanent home for the children whose parents were getting older. The decision to reinstitutionalize gradually increased for both groups of parents as the years passed.

Other perspectives on the deinstitutionalization movement will be presented at this point.

A review of the national trends in deinstitutionalization reveals that there is actually very little progress towards the depopulation of institutions for the mentally retarded (Conroy, 1977). Releases from large institutions have substantially increased but the rate of readmissions has increased more rapidly. Many residents have been relocated to newer and smaller institutions. This has manifested itself as inter-institutional relocation. People are released, but more and more are returning. Conroy (1977) has stated that public pressure to get people out of institutions has outstripped pressure to create normalizing community service systems.

Coexisting with the trend of deinstitutionalization is the emergence of a countertrend towards it. Payne (1976) has studied parent attitudes towards deinstitutionalization and small group homes. The results of 150 questionnaires were obtained from parents of mentally retarded persons in large institutions. Overall, the parents were in favor of maintaining the institution and were skeptical of the advantages of small group homes. More specifically, they felt that large institutions offered advantages that were good enough to keep the facility going. The parents also felt that small group homes offered some advantages, particularly for more mildly retarded individuals. The parents asserted that the large institution was better because it was a permanent home for retarded

persons, a place where their children could stay after they died.

Throne (1979) questions the deinstitutionalization movement on conceptual, scientific, and moral grounds. First, Throne feels that all human communities consist of many institutions. Group homes, family homes, and residential facilities are all institutions. and therefore the concept of deinstitutionalization is a false one. Second, Throne's research provided evidence that quality of care varied among the smaller institutions. The net result was the notion that there was no significant difference between institution size per se and quality of care. It was suggested that operant techniques be employed in every kind of institutional setting; Throne asserted that optimal institutional settings for the mentally retarded may be brought about by the incorporation of behavior modification techniques. Finally, since all kinds of institutions can be managed and organized effectively by empirical methods, Throne stated that the deinstitutionalization movement distracts us from solving institutional problems in a scientific way.

A review of the literature reveals that there is no one best living arrangement; what setting is beneficial for one resident can be destructive for another. In spite of the many articles that discuss the topic of deinstitutionalization, no truly general conclusions can be extrapolated due to the preponderance of variables that must be controlled in an objective evaluation of the merits and weaknesses of deinstitutionalization.

REFERENCES

Bell, N. J. I.Q. as a factor in community lifestyle of previously institutionalized retardates. Mental Retardation, 1976, 14, 29-33.

Birenbaum, A. and Re, M. A. Resettling mentally retarded adults in the community--almost 4 years later. American Journal of Mental Deficiency, 1979, 83, 323-329.

Cohen, H., Conroy, J. W., Frazer, D. W., Snelbecker, G. E., and Spreat, S. Behavioral effects of interinstitutional relocation of mentally retarded residents. American Journal of Mental Deficiency, 1977, 82, 12-18.

Conroy, J. W. Trends in deinstitutionalization of the mentally retarded. Mental Retardation, 1977, 15, 44-46.

Ellis, N. R., Bostick, G. E., Moore, S. A., and Taylor, J. J. A follow-up of severely and profoundly mentally retarded children after short-term institutionalization. Mental Retardation, 1981, 19, 31-35.

Gilbert, K. A. and Hemming, H. Environmental change and psycholinguistic ability of mentally retarded adults. American Journal of Mental Deficiency, 1979, 83, 453-459.

Intagliata, J. and Willer, B. Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes. American Journal of Mental Deficiency, 1982, 87, 34-39.

Kleinberg, J. and Galligan, B. Effects of deinstitutionalization on adaptive behavior of mentally retarded adults. American Journal of Mental Deficiency, 1983, 88, 21-27.

MacEachron, A. E. Institutional reform and adaptive functioning of mentally retarded persons: a field experiment. American Journal of Mental Deficiency, 1983, 88, 2-12.

Nihira, L. and Mihira, K. Jeopardy in community placement. American Journal of Mental Deficiency, 1975, 79, 538-544.

Payne, J. E. The deinstitutional backlash. Mental Retardation, 1976, 14, 43-45.

Reagan, M. W., Murphy, R. J., Hill, Y. F., and Thomas, D. R. Community placement stability of behavior problem educable mentally retarded students. Mental Retardation, 1980, 18, 139-142.

Scheerenberger, R. C. and Felsenthal, D. Community settings for m.r. persons: satisfaction and activities. Mental Retardation, 19[illegible] 15, 3-7.

Schroeder, S. R. and Henes, C. Assessment of progress of institutionalized and deinstitutionalized retarded adults: a matched-control comparison. Mental Retardation, 1978, 16, 147-148.

Seltzer, M. M., Seltzer, G. B. and Sherwood, C. C. Comparison of community adjustment of older vs. younger mentally retarded adults. American Journal of Mental Deficiency, 1982, 87, 9-13.

Sutter, P. Environmental variables related to community placement failure in mentally retarded adults. Mental Retardation, 1980, 18, 18-20.

Throne, J. M. Deinstitutionalization: too wide a swath. Mental Retardation, 1979, 17, 171-174.

Vitello, S. J., Atthowe, Jr., J. M., and Cadwell, J. Determinants of community placement of institutionalized mentally retarded persons. American Journal of Mental Deficiency, 1983, 87, 539-545.

Willer, B. and Intagliata, J. Comparison of family-care and group homes as alternatives to institutions. American Journal of Mental Deficiency, 1982, 86, 588-595.